

# **Health Status and Needs Assessment of Native Americans in Maine: A Follow-Up Report**

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## **Background to this Report**

At a conference to address the feasibility of developing collaborative efforts to address health disparities experienced by Native Americans in New England, the Maine Bureau of Health (BoH) presented an assessment of the health needs of its American Indian residents. The conference was sponsored by the U.S. Health Care Financing Administration, the U.S. Health Resources and Services Administration and the Indian Health Services. The final report from that presentation, Health Status and Needs Assessment of Native Americans in Maine: Final Report, was written in January 2000.

An unexpected finding of the January 2000 report was a significantly higher decline in cardiovascular disease (CVD) related mortality among American Indians than among the general population of Maine. The report stated:

“The apparently significant decline in rate of deaths due to cardiovascular disease in Maine Native Americans and their dramatic difference with the comparable rates in Maine’s general population requires in-depth evaluation. Preliminarily, it seems that at least three factors may play a role: changes in the population denominator, misclassification of race on death certificates and increasing access to preventive health information and services.”

To address the hypothesis that the results may have been due to racial misclassification on death certificates, the BoH collaborated with four Maine tribes to assess the validity of racial coding of American Indians on Maine death certificates. This report presents the results of these follow-up analyses.

## **METHODS**

To assess the impact of the denominator, the percent change in denominator for each of the 5 year periods used to assess mortality rates was computed.

To assess reporting error on death certificates, four Maine tribes provided a list of all members removed from their tribal register from 1978 to 1997. Additionally, each tribe provided the number of people on the tribal register by year and gender for use as denominator data in tribal-specific calculations.

Using a deterministic matching methodology, BoH attempted to match the tribal lists to the BoH death certificate files with the following data fields: last name, first name, date of birth, and social security number. Matched records were analyzed for discordance of racial coding.

To assess coding and data entry, all records were reviewed visually for coding accuracy. Using the corrected race codes from both record reviews, the overall and tribal racial miscoding rates were calculated.

The January 2000 report presented CVD-related mortality rates for four 5-year periods: 1978-1982, 1983-1987, 1988-1992 and 1993-1997. The report presented CVD-related mortality rates for immediate cause of death only. Using the updated racial codes, BoH recalculated CVD-related death rates for immediate cause. Two additional sets of

analyses were done: 1) CVD-related mortality defined as mention of any CVD-related mortality on the death certificate, as either the immediate or any ~~underlying~~ related cause of death and 2) age-specific mortality for ages 25-64 and 65 and older.

The possibility of an analysis error was also considered. All analytic files and programs were reviewed for accuracy.

CVD-related mortality was defined as an ICD-9 code of 390 to 448. BoH denominators were used for all Maine and Franklin County analyses. U.S. Census Bureau estimates were used for American Indian analyses. Tribal-specific analyses used tribal populations. Mortality rates and 95% confidence intervals are presented as the rate per 100,000 and are age adjusted to the 1940 US Standard Population.

The sample size was not sufficient to do a mortality analysis for each tribe. However, the Passamaquoddy and Penobscot tribes have a similar history of health-care access and CVD-related disease prevention programs. Data from these two tribes were therefore combined and there were sufficient numbers to do an analysis. The Passamaquoddy and Penobscot analysis includes only records identified as tribal members by the respective tribe. The category “American Indian” includes all records with a racial coding of “American Indian”, including records not matched with the tribal register. For comparison purposes, rates for Franklin County (the Maine county with the lowest rates of CVD-related disease) were also calculated.

### **Limitations:**

The analyses only included an assessment of racial miscoding for Maine American Indians who were tribal members of four of the five Maine tribes. One tribe did not participate in the assessment and there is no register of non-tribal members. Our findings will therefore underestimate the total CVD-related mortality experience of Maine American Indians.

## **RESULTS**

### **Analysis Error**

A programming error was discovered which had resulted in an undercount of American Indian CVD related deaths for the years 1995-1997. This was corrected when the rates were recalculated.

### **Racial Validity Assessment -**

#### Reporting Error (Tribal Registry Validation Assessment – see Table 1)

From 1978 to 1997, a total of 375 persons were removed from the tribal registers of the four Maine tribes. However, 140 were not included in the assessment of racial coding (55 died either before 1978 or after 1997, 52 died out-of-state and 33 couldn't be found in Boh files using the deterministic matching method). Of the 234 records included in the analysis, 30 were reported on the death certificate as ‘white’, an error rate of 13%. Both the number of records available for analysis and the miscoding rate varied for each tribe:

Maliseet 6 records, 16% miscoded; Micmac 3 records, 25% miscoded; Passamaquoddy 2 records, 4% miscoded and Penobscot 19 records, 14% miscoded.

Miscoding and Data Entry Validation Assessment

The overall error rate due to miscoding and data entry errors was 15%. Tribal rates varied: Maliseet 7 records, 18% miscoded; Micmac 4 records, 33% miscoded; Passamaquoddy 5 records, 11% miscoded and Penobscot 19 records, 14% miscoded.

Considering the two validation assessments, the overall racial miscoding error rate was 28%. The rate varied by tribe from: Maliseet 13 records, 34% miscoded; Micmac 7 records, 58% miscoded; Passamaquoddy 7 records, 16% miscoded and Penobscot 38 records, 27% miscoded.

**Table 1. Rate of Miscoding American Indian Race by Tribe**

<b>Tribe</b>	<b>Reporting Error</b>	<b>Coding/ Data Entry Error</b>	<b>TOTAL</b>
	<b><i>Number (%)</i></b>	<b><i>Number (%)</i></b>	<b><i>Number (%)</i></b>
<b>Maliseet</b>	6 (16%)	7 (18%)	13 (34%)
<b>Micmac</b>	3 (25%)	4 (33%)	7 (58%)
<b>Passamaquoddy</b>	2 (4%)	5 (11%)	7 (16%)
<b>Penobscot</b>	19 (14%)	19 (14%)	38 (27%)
<b>Total</b>	<b>30 (13%)</b>	<b>35 (15%)</b>	<b>65 (28%)</b>

**Cardiovascular-Disease Related Mortality**

**CVD-related Mortality –Immediate Cause Only (see Table 2)**

The apparent dramatic decline in death rates related to cardiovascular disease in American Indians compared with the rest of Maine that was reported in January 2000 was not seen in the re-analysis using the corrected racial coding data. There was no significant difference in the rate of decline of cardiovascular-disease related mortality between American Indians and other Mainers.

**Table 2. CVD-related Mortality –Immediate Cause Only**

<b>Before Correction of American Indian Race</b>				
	<b>1978-82</b>	<b>1983-87</b>	<b>1988-92</b>	<b>1993-97</b>
Maine	244.1	220.8	178.9	160.0
American Indian	357.8	180.1	143.1	80.5
<b>After Correction of American Indian Race</b>				
	<b>1978-82</b>	<b>1983-87</b>	<b>1988-92</b>	<b>1993-97</b>
Maine	244.1	220.8	178.5	156.5
American Indian	357.8	199.2	174.4	185.6
Passamaquoddy and Penobscot	162.0		100.9	

**CVD-related Mortality -- Any Mention (see Table 3)**

CVD-related mortality rate for the state as a whole declined 19%, from 300.1 (95% CI 297.5 – 302.6) to 241.9 (95% CI 239.8 – 244.0). This decline was statistically significant. Similarly, Franklin County experienced a statistically significant decline from 262.4 to 224.8. Rates for both 10-year periods in Franklin County were statistically lower than the state rates.

The mortality rates for all Maine American Indians declined 16% (388.1 to 326.7). The decline was not statistically significant. The rates were statistically higher than the rates for all of Maine. The mortality rates for all Maine Passamaquoddy and Penobscot Tribes declined 36% (285.7 to 183.9). The decline was not statistically significant. The rates were statistically similar to the rates for all of Maine.

**Table 3. Any mention of CVD-related Mortality**

	1978-1987				1988-1997				% Change
	Number of Deaths	Age-Adjusted Death Rate	95% CI		Number of Deaths	Age-Adjusted Death Rate	95% CI		
			(lower)	(upper)			(lower)	(upper)	
Maine (all races)	67,863	<b>300.1</b>	297.5	302.6	66,746	<b>241.9</b>	239.8	244.0	<b>19%</b>
Franklin County (all races)	1,387	<b>262.4</b>	247.2	277.7	1,402	<b>224.8</b>	211.4	238.3	<b>14%</b>
American Indian	113	<b>388.1</b>	317.2	459.1	143	<b>326.7</b>	273.4	380.1	<b>16%</b>
Passamaquoddy and Penobscot	45	<b>285.7</b>	208.4	382.3	42	<b>183.9</b>	132.5	248.6	<b>36%</b>

**Age-specific analysis of CVD-related mortality (See Table 4)**

For the state of Maine, there was a statistically significant decline in the CVD-related mortality rate of 29% (202.4 to 143.1) among ages 25-64 and 10% among age 65 and older (3824.0 to 3405.5). However, for Franklin County, neither the 8% decline among 25-64 year olds, nor the 10% decline among those 65 and older was statistically significant. The rates for those age 65 and older were statistically lower than those for the state as a whole (but not for those age 25-64).

For all Maine American Indians, there was no change in the rates for ages 65 and older. The rates were not statistically different from the state. For the age group 25-64, there was a 31% decline but it was not statistically significant. However, the rates were statistically higher than the state rates for both time periods. For the Passamaquoddy and Penobscot Tribes neither the 50% decline in the 18-64 year olds, nor the 26% decline among those age 65 and older, were significant. However, the numbers were very small, limiting the ability to assess statistical differences. The rates for age 65 and older were significantly lower than the state rates for both time periods.

The same analysis was done using related cause only. While all observed trends were in the same direction, they were weaker (data not presented).

**Table 4. Age-specific analysis of CVD-related mortality)**

<b>Age 25-64</b>									
	1978-1987				1988-1997				% Change
	Number of Deaths	Rate	95% CI		Number of Deaths	Rate	95% CI		
			lower	upper			lower	upper	
Maine (all races)	11,167	<b>202.4</b>	198.6	206.2	9,183	<b>143.1</b>	140.2	146.0	<b>29%</b>
Franklin County (all races)	197	<b>153.3</b>	131.9	174.7	205	<b>141.2</b>	121.9	160.5	<b>8%</b>
American Indian	50	<b>280.9</b>	208.5	370.3	54	<b>193.3</b>	145.2	252.2	<b>31%</b>
Passamaquoddy And Penobscot	18	<b>185.5</b>	109.9	293.2	14	<b>93.4</b>	51.1	156.7	<b>50%</b>
<b>Age 65 and Over</b>									
	1978-1987				1988-1997				% Change
	Number of Deaths	Rate	95% CI		Number of Deaths	Rate	95% CI		
			lower	upper			lower	upper	
Maine (all races)	56,282	<b>3824.0</b>	3792.4	3855.6	57,235	<b>3405.5</b>	3377.6	3433.4	<b>11%</b>
Franklin County (all races)	1,175	<b>3521.9</b>	3320.5	3723.3	1,190	<b>3185.6</b>	3004.6	3366.6	<b>10%</b>
American Indian	60	<b>3134.8</b>	2392.2	4035.1	86	<b>3181.7</b>	2544.9	3929.4	<b>-1%</b>
Passamaquoddy And Penobscot	26	<b>2509.7</b>	1639.4	3677.3	27	<b>1860.8</b>	1226.3	2707.4	<b>26%</b>

## Conclusions

This follow-up study yielded very significant, highly valuable findings regarding the validity of racial coding on death certificates of Maine Native Americans and the resulting impact on assessing health disparities experienced by Maine's Native American residents. These findings include:

- The overall racial miscoding rate of 28% was unexpectedly high and had a large impact on CVD-related mortality among American Indians when compared to the rest of Maine.
- While the racial miscoding rate varied from 11% to 33%, the tribal rates based on the large and more stable numbers were all close to 15%. There is no reason to believe that this rate of about 15% would really differ significantly by tribe in Maine. This rate of racial miscoding is very consistent with other studies done in other parts of the U.S.
- The revised rates of deaths due to cardiovascular disease (CVD) are still an underestimation of American Indian mortality: 28% of the records were not found in Maine's death certificate files, at least 50% of that number, however, are known to have died out of state; one tribe did not participate; and there was no methodology to assess American Indians who are not affiliated with a tribe.
- Within these limitations, it appears that members of the Passamaquoddy Tribe and Penobscot Nation appear have better cardiovascular health outcomes than Mainers as a whole. Conversely, American Indians not affiliated with these two tribes consistently had higher mortality rates than other Mainers.
- There are higher rates of CVD-related mortality in American Indians in the younger population age 25-64.
- Changes in the denominator (growth in the Native American population total) may have had an effect on the rapid decline in CVD-related mortality rates observed, especially in the period from 1978-1993. More work needs to be done to quantify this impact.

Put simply: cardiovascular disease-related health disparities experienced by Maine Native Americans have not disappeared. Our study confirms that racial miscoding on death certificates is significant in Maine. Miscoding rates are likely to be similar to what has been documented in other studies around the country. This miscoding has resulted in an under-estimation of cardiovascular-related health disparities experience by Maine's Native American population.

At the same time, our study data specific to the Penobscot Nation and Passamaquoddy Tribe support the positive impact that Tribal Health Centers are having in reducing cardiovascular disease mortality over time. Health leaders from these Maine tribes undoubtedly have much to teach all Mainers about improving health and health care, and eliminating health disparities.